



# WHY MEDICAL AID IN DYING SHOULD BE EXPANDED IN THE US

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## ABSTRACT

Despite an aging population with more degenerative diseases being present than ever before, death is rarely talked about in the US. Palliative care has risen to meet these challenges but there is more to end of life care than keeping someone alive. Medical Aid in Dying (MAID) allows physicians to supply someone with life ending medication based on a set of criteria. In some US states there are very limited MAID laws. In Canada, there is a relatively more permissive system around MAID. Most people who wish to end their life due to what they consider unbearable circumstances have access. Through case studies and research, it was found that in areas with MAID laws there was more protection for people with degenerative diseases from suicide. Aiding in suicide is illegal so many people take their lives alone and prematurely before their condition progresses to a point where they cannot. In places with limited MAID laws like Oregon, the criteria that the person has to self-administer the medication could prompt people with conditions that debilitate to take the medication sooner than they would like. Canada's policies allow for advanced consent which side steps that complication. Since there is wider access across more diseases, less people are likely to commit suicide prematurely and alone.

**KEYWORDS:** Physician assisted suicide, Medical Aid in Dying, Death with Dignity.

## INTRODUCTION

Through industrialization, improvements in sanitation, better living standards, vaccines, and breakthroughs in medicine, the circumstances of death have changed in much of the world from pestilence and famine to delayed degeneration. With this change comes the responsibility to provide care for the dying and allow them a death with grace and dignity. Much of our medical system is set up to keep people alive for as long as possible, but there comes a point where that mindset is no longer beneficial. The shift in perspective from a pursuit of extended life to an acknowledgment that the end is close and symptoms need to be treated and not cured has come about in the form of palliative care. Hospices have emerged around America to aid in the dying process for terminally ill patients. Even though options for care at the end of life have expanded, options for ending your life have not in most states. Many people live on through intense discomfort even though they have explicitly stated that they would prefer death to a continued existence. Their preference for death is not respected because aiding in 'suicide' is illegal. The stigmatization of death has prevented many from providing their loved ones with a dignified end. There are two ways in which America's stringent policies toward MAID, or lack thereof, fail people who have a degenerative disease. First, it prompts people to take their lives prematurely for fear that as their condition progresses, they will no longer have the physical or mental capacity. Second, it isolates those who wish to die from their loved ones for fear of criminal investigation. **This paper attempt to make the case to expand accessibility to MAID by evaluating America's policies in comparison to Canada's lenient policies toward MAID.**

## Medical Aid in Dying or Death with Dignity

MAID allows someone fitting a range of criteria to request from their physician a prescription for a life ending medication. Family and friends cannot be criminally prosecuted for being with the person when they choose to take the medication.

## Methods

This paper includes two main sources of information: Canada's third annual report on medical assistance in dying and Oregon's 2021 Death with Dignity data summary. Data is derived from reports from medical professionals in both areas and is a quantitative, primary source. This paper uses qualitative comparative analysis on these two sources to determine which policy is preferable. The other major source of information comes from one case study, about a person denied MAID. All sources are peer reviewed and reputable.

## Case Study

The 1st case study discussed is about a male individual named Naggy, who had Huntington's disease - a fatal, inherited condition in which nerve cells in the brain slowly degenerate and die (Huntington's Disease, n.d.). As the disease progresses, it leaves people immobile, with less and less cognitive function. Under Oregon's current laws, these types of degenerative diseases do not qualify for Death with Dignity. Naggy was independent and did not want to be stripped of autonomy in his ability to choose how he died. His worst fear was to end up like his father, tied down to a hospital bed without meaningful control over himself. He was worried that as the disease progressed, he would be mentally and physically unable to take his own life as he wanted. So, with many good years left and without his loving wife by his side, he took his own life while he was still able to

do so. While this was the end for Naggy, it was not the end for his wife Jan. She had to endure a four-month police investigation for suspected homicide, in a time when she should have been able to peacefully grieve for her late husband (Pastine, 2015).

This case study is characteristic of thousands of similar stories, where Naggy had to do what no individual should have to. Those dying of terminal illness or a degenerative condition should have the right to die with family and loved ones by their side. They should be able to die in the time they feel is right, without being hastened by the impending debilitation of their condition. For cases like these, this is the only possible outcome. In contrast, Canada's policies toward MAID offer a new and needed perspective on how to treat death and who has primacy in the end of life.

## Overview of Canada's Policy

In 2016, Canada passed one of the world's most permissive MAID policies into law. The stark difference in criteria between Canada's and Oregon's policies make it ideal for qualitative comparative analysis. The relevant criteria to this paper for accessing MAID in Canada is that the person must have a "grievous and irremediable medical condition" (Government of Canada, 2016, 241.2). This means that:

- they have a serious and incurable illness, disease or disability;
- they are in an advanced state of irreversible decline in capability;
- that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable. (Government of Canada, 2016, 241.2)

Oregon legalized MAID in 1997 through the Death with Dignity Act (DWDA). It was one of the first places in the world to do so as well as the first US state. Since 1997 only a few other states have legalized it including Colorado, the District of Columbia, Hawaii, Maine, New Jersey, New Mexico, Vermont and Washington. Oregon has the best documentation of MAID outcomes and research, making it the best state to compare with Canada. We cannot compare all of the US to Canada because of the lack of a federal Death with Dignity law.

The relevant qualifications that differ from Canada's criteria are that:

- (1) the person must be terminally ill with 6 months left to live as determined by two physicians
  - (2) the person must be able to self-administer the medication.
- People pursued MAID for the following reasons: loss of autonomy, loss of dignity, pain, and inability to engage in everyday or enjoyable activities.

## Canada's and Oregon's policies differ in three relevant ways:

### 1. The Range of Degenerative Diseases that can be treated with MAID.

In 2021 MAID accounted for 3.3% of all deaths in Canada (Government of Canada, 2022). In Oregon MAID deaths only account for 0.655% of total deaths (oregon.gov, 2022). The variety of underlying conditions that prompted interest in MAID was also greater in Canada. People with neurological conditions such as Parkinson's disease, multiple sclerosis, and dementia were able to access MAID where in Oregon people with ALS were the primary recipients. This is largely because many conditions play their course over periods longer than six months and debilitate to the point where a Oregon resident can no longer be con-

sidered competent under its current policy. People with a variety of conditions that don't fall under Oregon's MAID criteria want the right to die. The variety of conditions that are permitted under Canada's policy as well as the data showing that people with those conditions want MAID shows that Oregon's policy is not adequate to serve all those close to death. The implication of Oregon's limited policy is that people who do not fit the criteria end up suffering with a quality of life that they do not find acceptable or they take their own life. Canada's permissive system shows that people without terminal illness and more than 6 months left to live still access MAID.

## 2. What stage of the illness grants access to MAID

In Oregon a person has to be terminally ill with 6 months left to live to access MAID. In Canada there is no time limit as long as the person fits all other criteria. 2.2% of MAID deaths in Canada are not reasonably foreseeable and the rest fall in this vague language of being 'reasonably foreseeable' (Government of Canada, 2022). This policy difference allows people with dementia and long-term disease to access MAID.

## 3. Administration of the Medication

In Oregon the medication has to be self-administered and is usually taken orally. There is a certain amount of physical ability that comes with these tasks. If a person's physical health deteriorates to the point where they can't administer the medication, they can no longer access MAID. This can prompt people to take medication prematurely out of the fear that their condition will progress to a point where it is no longer possible for them to do so. In Canada, a person can provide advanced consent to the procedure. This means that if a person's condition has advanced beyond a stage, they do not have to provide consent and the physician can administer the medication themselves. This policy difference ensures that people are able to stay in this world for as long as possible without the fear of not being able to administer the medication.

## Discussion

The lack of MAID laws in most of the US pushes those with degenerative diseases to take their own lives prematurely without the comfort of loved ones. Even places like Oregon, that have taken a big step in providing people with a death on their own terms, have a lot to improve upon. It should be noted that only having MAID laws without an effective palliative care system is morally corrupt. Death should not be a ready alternative to a failing system. The US ranks 9th in the world in quality of death based on palliative and healthcare environment, Human resources, affordability of care, quality of care, and community engagement (Goodman & Fishman, 2015). More people die at home in the US compared to other regions which is also preferred (Kliff, 2016). In Canada, only 44.2% of MAID deaths occurred at home while 28.6% took place in hospitals (Government of Canada, 2022). In Oregon, 95% died at home (oregon.gov, 2022). A continued dedication to end of life care will ensure that MAID is administered ethically and is something the person feels is best for them.

People with degenerative diseases are more likely to commit suicide than the average population. Sometimes, this desire can be attributed to depression and the feeling of being a burden. Permissive MAID laws allow such individuals access to mental health services and counseling that often they previously wouldn't utilize. Palliative care practices can do a lot to improve quality of life. Having MAID as an option allows the system to provide better palliative care by finding the people who need it.

In both the US and Canada, a substantial number of people never administer the medication. Despite not being used, people say it brings them great relief from anxiety knowing it is there if they need it (Goodman & Fishman, 2015). Not having to worry about a painful death which the patient has little control over allows people to focus more on living. There is no longer a worry of an existence that is too unbearable. MAID also allows people to say goodbye to their loved ones and schedule their death at a time that suits them. In Canada, more people are able to die in the arms of their loved ones without the fear of criminal prosecution. In the US, there is often no such option.

## Conclusion

The systems currently set up in the US force some people with degenerative conditions to take their lives prematurely and in a way where loved ones cannot be present. People may say the use of 'prematurely' is inappropriate because it implies that there is a time in which someone should be able to take their own life. This paper affirms that in certain contexts death should be a right. There is nothing abhorrent about dying on your own terms with a degenerative condition. The word 'prematurely' is vital here because for some people there does come a time when death is the preferred option. A society should support people in a way that that decision can come as late as possible. Canada's MAID laws do that by stopping people from committing suicide or using MAID before their condition debilitates them to the point where they cannot. The US palliative care system does that by providing people with a quality of life that they find acceptable. The US needs both systems working in tandem to provide people with degenerative conditions a death with dignity. This paper speaks in favor of expanding MAID laws in the US at a federal level and in the wording of the law itself by looking at how Canada has implemented MAID. Canada's policy serves more people and lowers suicide by allowing advanced consent. A quote from a study looking at the experiences and perspectives of people opting for MAID aptly sums up the

motivation behind this paper: *"I feel that if you want to live until the very last moment and have tubes and machinery keep you alive ... then so be it. Go for it. I also believe that if I don't feel this way, you should respect my wishes as well. ... I don't want to have to take matters into my own hands. I want options. I want choice. I deserve that. We all deserve that."* (Patient H) (Nuhn et al., 2018, pg. 24). MAID is a matter of autonomy, protection and choice at the end of life. The US should federally respect a person's right to die with dignity.

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